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Increasingly, the cultural beliefs and values of participants are being recognized as important factors in genetic counseling. Despite recommendations to increase the cultural sensitivity of genetic counseling, such programs have not been developed or evaluated. The objectives of this study are to develop a Culturally Tailored Genetic (CTGC) protocol for high-risk African American women and evaluate its impact on decision-making and satisfaction about BRCA1/2 testing, quality of life, and cancer control practices. A secondary objective of this study is to identify African American women who are most and least likely to benefit from CTGC vs. SGC. The key research accomplishments achieved during the past year include completing the transfer of the study to the University of Pennsylvania Medical Center, hiring study personnel, developing the culturally tailored genetic counseling protocol, and establishing mechanisms for subject recruitment.

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A. INTRODUCTION

Five to 10% of all breast cancer cases have been attributed to two breast-ovarian cancer susceptibility genes called BRCA1 and BRCA2. Genetic counseling and testing for BRCA1/2 mutations is now available through clinical research programs using standard counseling protocols. The goal of pre-test counseling is to facilitate informed decision making about whether to be tested and to prepare participants for possible outcomes. The goal of post-test counseling is to provide information about risk status, recommendations for surveillance, and options for prevention. However, previous research on genetic counseling suggests that African American and Caucasian women differ in their attitudes about and responses to pre-test education and counseling. Increasingly, the cultural beliefs and values of participants are being recognized as important factors in genetic counseling. Despite recommendations to increase the cultural sensitivity of breast cancer risk counseling, such programs have not been developed or evaluated. Therefore, the purpose of this study is to develop a Culturally Tailored Genetic Counseling (CTGC) protocol for African American women and evaluate its impact compared with Standard Genetic Counseling (SGC) in a randomized clinical trial. This research is linked with Dr. Hughes' Career Development Award and has the following primary technical objectives:

(1) To evaluate the relative impact of CTGC vs. SGC on decision-making and satisfaction about BRCA1/2 testing. Compared to SGC, CTGC will lead to higher rates of test acceptance and satisfaction with testing decisions. These effects will be mediated by increases in perceived benefits and decreases in perceived limitations and risks of genetic testing.

(2) To evaluate the impact of CTGC vs. SGC on quality of life and health behaviors following BRCA1/2 testing. Compared to SGC, CTGC will lead to larger decreases in general and cancer-specific distress, greater increases in adherence to cancer screening guidelines, and lower rates of prophylactic surgery. Reductions in psychological distress will be mediated by increased use of spiritual coping strategies.

Secondary Aim

To identify African American women who are most and least likely to benefit from CTGC vs. SGC. We predict that the relative benefits of CTGC will be greatest for women with greater endorsement of African American cultural values and those identified as BRCA1/2 carriers.

B. BODY

The research was transferred to the University of Pennsylvania Medical Center in February 2002. The first year of the study at the University of Pennsylvania focused on (1) completing actions to complete the transfer of the project, (2) hiring study personnel, and (3) developing the culturally tailored genetic counseling (CTGC) protocol. Because approval of human subjects use was not provided by the Contracting Officer during the past year, we were not able to initiate study recruitment. However, we have completed actions to develop mechanisms for subject enrollment. These activities are described in sections 3 and 4. This project is linked with Dr.

Hughes' Career Development Award (CDA) and activities regarding professional development are provided below in section 5.

(1) Transfer of Data Management System. We have completed actions to transfer the data management system to the University of Pennsylvania Medical Center. This system is a Microsoft Access relational database that was created to store research data (i.e., subject contact information, questionnaire data). As part of this transfer, research personnel (see #2 below) completed in-person training with the database developer to ensure that they were knowledgeable about system components and procedures. In addition to transferring the data management system, we also completed actions to obtain approval of human subjects use from the University of Pennsylvania Medical Center and the Department of the Army Humans Subjects Review Committee. However, during the past year, we did not initiate subject accrual because this project was awaiting notification of final approval by the Department of the Army Contracting Officer, per Department of the Army requirements.

(2) Study Personnel. During the past year, we have recruited a Bachelor's level research assistant and a Master's level data manager to complete telephone interviews and oversee data collection and entry, respectively. In addition, we have hired a Master's level Certified Genetic Counselor to deliver the study protocols. To ensure that the process and format of our counseling protocols are consistent with those used in clinical genetic counseling, our new genetic counselor completed training on cancer risk counseling and breast cancer genetics through the Cancer Risk Evaluation Program at the Abramson Cancer Center. Training on cultural and ethnic issues in genetic counseling and cancer prevention and control was also provided by Dr. Hughes.

(3) Development of the Culturally Tailored Genetic Counseling Protocol (CTGC). Because use of human subjects (including focus group participants) was not provided by the Contracting Officer during the past year, we were not able to initiate subject recruitment. However, we did complete several activities to develop the culturally tailored genetic counseling protocol. These activities included completing analyses to describe the prevalence of cultural beliefs and values among African American women at risk for having a BRCA1/2 gene alteration and to evaluate the association between these beliefs and values and participation in genetic risk assessment (see manuscript in Appendix 1). Subjects were 28 African American women who had previously participated in focus interviews before the study was transferred to the University of Pennsylvania Medical Center. Overall, 61% subjects received BRCA1/2 test results and 39% declined. Compared to decliners, women who received BRCA1/2 test results reported significantly higher levels of future temporal orientation. While sociodemographic factors were not associated with test acceptance; utilization of genetic testing was significantly lower among women with greater perceptions of familial interdependence (41% versus 91%, $p = .02$). Levels of spiritual faith were not associated with participation in genetic risk assessment; however, there was a trend for respondents who reported greater utilization of coping by working together with God when considering a difficult situation to be more likely to participate in genetic risk assessment and counseling (70%) compared to respondents who reported less utilization of this strategy (20%) ($p = .06$).

In addition to evaluating the association between cultural beliefs and values and participation in genetic risk assessment, we also evaluated the prevalence of these factors among African American women at risk for having a BRCA1/2 gene alteration to identify beliefs and values that should be addressed within the CTGC protocol. This work has shown that familial responsibilities and maintaining the quality of relationships with relatives are highly valued. For example, more than 80% of respondents reported that it was mostly or completely true that they were constantly aware of their responsibility to family members, individuals have an obligation to cooperate with family and friends, and sacrifices are made for relatives, while only 39% of respondents reported that it was mostly or completely true that their first responsibility is to themselves rather than family members. Relatives were also viewed as an important source of social support; 82% of respondents reported that is was mostly or completely true that family members turn to one another during a crisis and 71% reported that is was mostly or completely true that older family members are relied on for advice or guidance. Further, 60% of respondents endorsed the belief that people should not view themselves as independent of family or friends and 93% reported that it was true that they were always interested in what older relatives have to say.

In terms of religious coping, collaborative coping strategies were the most strongly endorsed by study participants. For example, more than 80% of respondents endorsed coping strategies in which they worked together with God to decide what a problem means and to develop solutions to difficult situations. In terms of temporal orientation, subjects reported the highest mean level of past temporal orientation and the most strongly endorsed aspect within this domain was related to the emotional impact of thinking about past events. For example, 86% of respondents reported that thinking about the past makes them very emotional and respondents who endorsed this belief were significantly more likely to participate in genetic risk assessment.

Because of the high level of endorsement of collaborative religious coping strategies and the importance of maintaining familial relationships, the CTGC protocol will focus on addressing these beliefs and values. This will be achieved through the use of genograms. Genograms are tools used in family systems therapy to document family relationships and allow for exploration of spiritual issues. For example, Eunpu (1997) used genograms in a genetic counseling setting to explore beliefs and attitudes of illness, loss, and genetic risk in families. Spiritually focused genograms have also been used with African American women to help clients reveal and use spiritual resources, which can then be employed in problem solving (Hodge, 2001; Dunn et al., 1999). Genograms have also been used in cancer risk counseling to explore family relationships (Daly et al., 1999). While genograms have been used to clarify family relationships (i.e., levels of closeness) and communication patterns (i.e., the frequency of communicating with family members) in prior studies (Daly et al., 1999), we will use genograms in the CTCG protocol to explore perceptions of responsibility to family members, sources of emotional and information support, and identify family members who may be influential in health care decisions. We will also use genograms to explore religious and spiritual issues related to coping with one's risk of developing cancer.

Because we could not complete the focus groups during the past year due to pending approval of human subjects use by the Contracting Officer, instead, we completed a series of literature reviews to develop a better understanding of the influence of cultural factors in cancer genetics

among African American women who have a personal or family history of breast cancer. Part of this work is included in our review paper (see manuscript in Appendix 1) on cultural issues in cancer genetics (Hughes, 2002). We identified several trends that are consistent with our prior work in this area (Hughes et al., 1997; Lerman et al., 1999) and our analysis of cultural beliefs and values among African American women at risk for having a BRCA1/2 gene alteration. First, rates of participation in genetic risk assessment and testing are likely to be lower than intentions to have genetic testing among African American women (Hughes et al., in press; Thompson et al., 2002; Kinney et al., 2001). Consistent with our findings related to the importance of family relationships and responsibilities, studies have shown that African American women have greater concerns about the implications of genetic test results on family members (Donovan and Tucker, 2000) and these concerns may be a barrier to participation in genetic counseling and testing (Thompson et al., 2002). These findings further support emphasizing the familial implications of genetic risk assessment as part of the CTCG. Several studies have also shown that levels of knowledge about breast cancer genetics are low among African American women (Hughes et al., 1997; Donovan and Tucker, 2000) and this may also be a barrier to participation in genetic counseling (Thompson et al., 2002).

(4) Development of Mechanisms for Subject Recruitment. During the past year, we have completed activities to establish mechanisms for subject recruitment. These efforts have focused on informing African American breast cancer support groups about the research program, developing a community-based physician referral network, and conducting in-services about the study with faculty and staff at the Abramson Cancer Center. Overall, responses to information about the upcoming availability our program have been positive among breast cancer support group facilitators. However, it was surprising that many of the support group facilitators were not aware of the availability of genetic testing for inherited breast cancer risk. This observation is consistent with empirical studies that have shown that African American women have less exposure to information about the availability of genetic testing for inherited breast cancer risk (Hughes et al., 1997; Donovan and Tucker, 2000). With regard to the community-based physician referral network, this resource consists of eight oncology and primary care practices with a large proportion of African American patients. These facilities are located throughout Philadelphia area. Once approval for the use of human subjects has been granted from the contracting office at the Department of the Army, Family History Forms will be made available at each referral site for women to self-refer for study participation.

(5) Career Development Activities. Because this project is linked with Dr. Hughes' career development award, a summary of the professional development activities that were completed during the last year is included in this report. During the past year, Dr. Hughes has become an integral member of the Cancer Screening and Outcomes program at the Abramson Cancer Center. She has also co-authored several peer-reviewed manuscripts related to the psychological and behavioral impact of genetic testing for inherited cancer risk. These manuscripts are directly related to the outcomes of this study and the experiences learned through working on these publications will facilitate Dr. Hughes' ability to generate peer-reviewed publications based on the data from this project. Dr. Hughes has also been invited to deliver presentations at one international scientific conference and at several other conferences held locally during the past year.

C. KEY RESEARCH ACCOMPLISHMENTS

During the past year, our efforts have focused on completing the transfer of the study to the University of Pennsylvania Medical Center, hiring study personnel, developing the culturally tailored genetic counseling protocol, and establishing mechanisms for subject recruitment. The length of time needed to receive approval for the use of human subjects was not anticipated; however, we been productive during the past year. We have recruited and trained an entirely new research team at the University of Pennsylvania Medical Center. In addition, we have identified cultural factors that should be address in the CTCG through our analysis of the prevalence and impact of cultural beliefs and values on participation in genetic risk assessment. Through this evaluation, we found that family relationships, religious coping style, and temporal orientation influence decisions to utilize genetic counseling. Our decision to focus on these cultural factors as part of the CTCG has been further supported by findings reported in other empirical research among African American women (Thompson et al., 2002; Donovan and Tucker, 2000). We have also established a community-based physician referral network for subject recruitment. This mechanism has been used in previous research designed to identify African Americans for participation in research on hereditary prostate cancer (Royal et al., 2000) and will ensure that we are able to accomplish our accrual goals within the remaining period of the study.

D. REPORTABLE OUTCOMES

Manuscripts Published with Grant Support

Hughes C. Cultural issues in cancer genetics. *Primary Psychiatry* 2002; 9:50-56.

Hughes C, Fasaye GA, LaSalle VH, Finch C. Sociocultural influences on participation in genetic risk assessment and testing among African American women. *Patient Education and Counseling*. In press.

Manuscripts Published as Part of Career Development Activities

Hughes C, Lerman C, Schwartz M, Peshkin BN, Wenzel L, Narod S, Corio C, Tercyak KP, Hanna D, Isaacs C, Main D. All in the Family: An evaluation of the process and content of sister's communication about BRCA1 and BRCA2 genetic test results. *American Journal of Medical Genetics* 2002; 107:143-150.

Schwartz MD, Peshkin B, Hughes C, Main D, Isaacs C, Lerman C. The impact of BRCA1/BRCA2 mutation testing on psychological distress in a clinic-based sample. *Journal of Clinical Oncology* 2002; 20:514-520.

Peshkin BN, Schwartz MD, Isaacs C, Hughes C, Main D, Lerman C. Utilization of mammography following BRCA1/2 testing. *Cancer Epidemiology, Biomarkers and Prevention* 2002; 11:1115-1118.

Cella D, Hughes C, Peterman A, Chang C-H, Peshkin BN, Schwartz MD, Wenzel L, Marcus A,

Lerman C. A brief assessment of concerns associated with genetic testing for cancer: The multidimensional impact of cancer risk assessment (MICRA). *Health Psychology* 2002; 21:564-572.

Audrain-McGovern J, Hughes C, Patterson F. Effecting behavior change: Awareness of family history. *American Journal of Preventive Medicine*. In press

Manuscripts Under Review and in Preparation

Hughes C, Peterson SK, Ramirez AG, Gallion KJ, McDonald P, Skinner S, Bowen D. The art and science of minority recruitment in cancer research. *Cancer Epidemiology, Biomarkers and Prevention*. Under Review.

Hughes Halbert C, Schwartz MD, Wenzel L, Lerman C. Cognitive appraisals following genetic testing for BRCA1 and BRCA2 mutations. *Journal of Behavioral Medicine*. Under Review.

Hughes Halbert C, Lynch H, Lynch J, Main D, Kucharski S, Rustgi AK, Lerman C. Colon cancer screening practices following genetic testing for Hereditary Nonpolyposis Colon Cancer (HNPCC) Mutations. *JAMA*. Under Review.

Hughes Halbert C, Mitchell E. Hereditary breast cancer in African Americans: Epidemiology and psychosocial aspects. Manuscript in preparation.

Longacre M, Collier A, Kessler LJ, Hughes Halbert C. Breast cancer prevention and control in African American women: An updated review. Manuscript in preparation.

Invited Lectures and Presentations Delivered by Dr. Hughes

"Sociocultural Influences on Participation in Genetic Risk Assessment among African American Women." The 6th International Symposium on Predictive Oncology and Intervention Strategies, Paris, France, 2002.

"Implications for the Human Genome Project for Ethnic Diversity Issues in Cancer Prevention." Keynote Address, Zeta Phi Beta Sorority Leadership Conference, Atlantic City, NJ, 2002.

"Managing Family Concerns and Making Medical Decisions. An Evaluation of Genetic Counseling Outcomes." Fox Chase Cancer Center, Philadelphia, PA, 2002

Abstracts Presented by Dr. Hughes at National Scientific Conferences

An Evaluation of Cultural Beliefs and Values among High-Risk African American Women. Presented at the Department of Defense Breast Cancer Research Program Era of Hope Meeting, Orlando, FL, 2002

Colon Cancer Screening Practices following Genetic Testing for HNPCC Mutations. Presented at the American Association for Cancer Research Frontiers in Cancer Prevention Research Conference, Boston, MA, 2002

E. CONCLUSIONS

During the past year of the study, our activities focused on completing the transfer of the project to the University of Pennsylvania Medical Center, hiring study personnel, developing the culturally tailored genetic counseling protocol, and establishing mechanisms for subject recruitment. Although we have not been able to initiate subject recruitment because approval from the Contracting Officer for the use of use approval of human subjects use was not provided until February 2003, the activities that we have completed during the past year are significant for several reasons. First, we have identified prevalent cultural beliefs and values among African American women at risk for having a BRCA1/2 gene alteration. Although prior studies have shown that concerns about the familial implications of genetic testing may be barriers to participation in genetic testing among African American women, our study is the first to evaluate the association between cultural factors and participation in genetic risk assessment in this population. In addition to exploring the prevalence and impact of cultural beliefs and values during the past year, we have also established a community-based referral network through which we will recruit subjects into the study during the next year.

F. REFERENCES

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Kinney AY, Croyle RT, Dudley WN, et al. Knowledge, attitudes, and interest in breast-ovarian cancer gene testing: a survey of a large African-American kindred with a BRCA1 mutation. *Preventive Medicine* 2001; 33:543-51.

Lerman C, Hughes C, Benkendorf JL, et al. Racial differences in testing motivation and psychological distress following pre-test education for BRCA1 gene testing. *Cancer Epidemiology, Biomarkers, and Prevention* 1999; 8:361-367.

Thompson HS, Valdimarsdottir HB, Duteau-Buck C, et al. Psychosocial predictors of BRCA counseling and testing decisions among urban African American women. *Cancer Epidemiology, Biomarkers Prevention* 2002; 11:1579-1585.

G. APPENDICES

See Attached for Manuscripts Published with Grant Support

APPENDIX

- Manuscripts published with grant support

Clinical Focus
Primary Psychiatry. 2002;9(5):50-56

Cultural Issues in Cancer Genetics

Chanita Hughes, PhD

Abstract

What role does culture play in cancer genetics research? Genetic counseling and testing for BRCA1 and BRCA2 mutations is increasingly being integrated into the clinical management of individuals who have a family history of cancer that is suggestive of inherited breast-ovarian cancer. While several studies have been conducted to understand the psychological, clinical, and familial impact of genetic testing, relatively little attention has been given to the role of cultural influences on the process of providing genetic counseling and testing services. Cultural factors such as beliefs and values and ethnic background are likely to play an important role in genetic risk profiles, decisions about participation in genetic risk assessment and testing, and responses to genetic risk information. This article reviews emerging literature on the role of cultural factors in cancer genetics research.

Introduction

A substantial amount of research has been conducted to understand the clinical, psychological, and familial impact of genetic testing for inherited breast cancer risk. For example, women who are found to carry a cancer predisposing BRCA1 or BRCA2 (BRCA1/2) mutation have an estimated 55% to 85% increased risk of developing breast cancer and a 15% to 60% increased risk of developing ovarian cancer.[1-3] Men who have a risk conferring the BRCA1/2 mutation are also at increased risk for developing prostate cancer.[1] Several studies have also shown that rates of communicating BRCA1/2 test results to family members are high[4-6]. However, genetic testing may have an adverse effect on family and personal relationships.

In a recent study, approximately one third of BRCA1/2 mutation carriers reported that their family or personal relationships had been affected by genetic testing, and of these, 50% reported that these relationships were more emotionally strained after genetic testing.[7] Data on the psychological impact of genetic counseling and testing continue to emerge, and recent studies have demonstrated that receiving BRCA1/2 test results may generate specific emotional reactions, such as anxiety or sadness, rather than have an adverse effect on overall psychological functioning.[8-14] Compared to women who did not carry a deleterious

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BRCA1/2 mutation, BRCA1/2 mutation carriers reported significantly greater levels of genetic testing-specific distress in a recent study.[15]

While there is an abundance of data on the clinical, psychological, and familial impact of genetic counseling and testing for inherited breast cancer risk, culture is increasingly being recognized as an important factor in cancer genetics research. Culture is defined as a framework of beliefs and values that shape behavior and influence the way in which information about illness is interpreted and used to make healthcare decisions.[16] Recent reviews have recommended increased consideration of cultural characteristics in cancer prevention and control research,[16,17] and several studies have explored how cultural factors influence outcomes within cancer genetics studies (ie, genetic testing decisions, responses to genetic risk information).

While there is an increasing emphasis on distinguishing the contributions of underlying beliefs and values that are derived from one's cultural worldview (racial or ethnic differences in cancer prevention and control behaviors)[18] data are limited on the influence of specific cultural beliefs and values on genetic counseling and testing outcomes. For this reason, this review focuses on empirical research that has addressed how cultural factors such as ethnic background influence (A) the prevalence of genetic risk factors; (B) interest in genetic testing; and (C) responses to education and counseling about hereditary breast cancer and genetic testing. A review of how ethnic background has influenced these outcomes is informative for identifying areas that should be addressed in future cancer genetics research.

Research is now being conducted to identify susceptibility genes that confer an increased risk of developing other forms of cancer (eg, prostate cancer susceptibility genes)[19,20] and investigators are now exploring interest in genetic testing[21-24] for these forms of hereditary cancer.

This review is designed to identify underlying themes and issues related to cultural influences in cancer genetics research. Because increased attention is being directed towards reducing or eliminating racial and ethnic disparities in cancer morbidity and mortality,[25,26] articles that address ethnic group differences among African-American and White women are the focus of this article.

Ethnic Differences in Cancer Risk

A substantial amount of research has demonstrated that ethnic background is an important factor in breast cancer risk and survival. For example, while breast cancer incidence rates are greater among White women than among women from other racial and ethnic groups (ie, African American, Hispanic, Asian), African-American women are at increased risk for developing early onset disease, have higher rates of advanced-stage breast cancer, and show reduced rates of breast cancer survival.[27-30]

Recent work suggests that ethnic differences in breast cancer risk may also be due to variations in genetic risk factors.[31] For example, although BRCA1/2 mutations account for only about 5% to 10% of all breast cancer cases,[32,33] the prevalence of three founder BRCA1/2 mutations (185delAG, 5382insC in BRCA1 and 617delT in BRCA2) is about 2.5% among women of Ashkenazi Jewish background.[1,34] Specific BRCA1/2 mutations have also been identified among other ethnic groups, including Icelanders (999del5 in BRCA2), Norwegians (1136insA in BRCA1), and African Americans (M1775R, 1832del5, and 5296del4 in BRCA1).[31] Furthermore, data from recent epidemiological studies suggest that the prevalence of deleterious BRCA1/2 mutations ranges between 12% to 21% among clinic-based samples of African-American women who have a personal and family history of breast and/or ovarian cancer.[35] While our understanding of BRCA1/2 mutations among African Americans is increasing, efforts to further understand the penetrance of BRCA1/2 mutations among this population may be limited because of reduced participation in cancer genetics research.

Interest in Genetic Risk Assessment and Testing

Several studies have shown that women in the general population and those who have a family history of breast cancer report a high level of interest in genetic testing for inherited breast cancer risk.[36-38] However, these studies were conducted before predictive testing was available, and findings from these studies were based on data collected from samples of women who had a low or moderate risk of having a BRCA1/2 gene alteration. However, one of the first studies to report actual rates of test acceptance found that only 43% of high-risk individuals identified from a hereditary breast cancer registry received BRCA1/2 test results.[14] While this study suggested that rates of genetic test acceptance may be lower than anticipated among high-risk individuals, a recent study found that 82% of high-risk probands (ie, the first index case affected with breast and/or ovarian cancer to have genetic testing) ascertained from breast cancer clinics utilized genetic testing and received BRCA1/2 test results.[39] However, a limitation of these studies is that the findings are based on samples that were ethnically homogenous. A study by Schwartz and colleagues[39] found that rates of genetic test acceptance did not differ among African-American and White women; however, African-American women made up only 5% of the study sample.

Previous research has shown that African-American women are significantly less likely to participate in an education session about hereditary breast cancer and genetic testing compared to White women.[40] Even though African-American women reported significantly greater expectations about the positive outcomes of genetic testing than White women,[41] only 49% of African-American women participated in a pretest education session about hereditary breast cancer and genetic testing compared to 68% of white women.[40]

While greater levels of cancer-specific distress may be a barrier to participating in education and counseling programs designed to provide information about hereditary cancer and genetic testing among African-American women,[40] it is possible that reduced participation in education programs that were conducted before actual testing was available may underestimate interest in testing among African Americans at high risk for having a BRCA1/2 gene alteration.

A recent study found that 82% of African Americans at high risk for having a BRCA1/2 gene alteration reported that they would definitely have genetic

testing.[42] However, our preliminary findings suggest that rates of participation in genetic risk assessment and testing may be lower among high-risk African-American women. Only about 60% of African-American women who had a family history of breast and/or ovarian cancer that was suggestive of inherited breast cancer susceptibility participated in genetic risk assessment and received BRCA1/2 test results.[43] The small number of studies that have focused on genetic counseling and testing specifically among African Americans is a significant limitation in our ability to understand the psychological and behavioral impact of genetic counseling and testing for inherited breast cancer risk among this population. However, we can anticipate these potential effects based on data from studies that have evaluated responses to breast cancer risk counseling and education.

Responses to Risk Education and Counseling

Previous research has shown that African-American women may have different needs and preferences for information about inherited cancer risk. For example, when compared to White women, African-American women were less knowledgeable about breast cancer genetics (ie, transmission of inherited cancer susceptibility).[41,44] Although there were no differences among African-American and White women in terms of overall perceptions of the limitations and risks of testing in one study,[4] more recent work has demonstrated that African-American women have greater concerns about the limitations and risks of genetic testing.[44] However, African-American women were significantly more concerned about their ability to handle the emotional impact of genetic testing results compared to White women in both studies.[41,44]

Only a few studies have evaluated ethnic differences in the impact of education about hereditary breast cancer and genetic testing. For example, African-American women who participated in an education program about hereditary breast cancer and genetic testing reported significantly greater genetic testing intentions and were more likely to provide a blood sample for storage and possible future testing following an education and counseling intervention about hereditary breast cancer compared to African-American women who received an education-only intervention.[40]

Although this study was conducted before predictive testing for BRCA1/2 mutations was available and participants were women who had a low-to-moderate risk of having a BRCA1/2 gene alteration, the effects of the education and counseling intervention were only observed among African-American women. There were no differences in genetic testing intentions or provision of a blood sample among white women who received the education and counseling intervention compared to white women who received the education-only intervention.[40] However, printed educational materials that were designed to provide information about hereditary breast cancer, BRCA1/2 genes in the Ashkenazi Jewish population, and information about the benefits, limitations, and risks of genetic testing, led to greater perceptions of the limitations and risks of genetic testing, increased levels of knowledge about breast cancer genetics, and decreased genetic testing intentions among Ashkenazi Jewish women at low risk for having a BRCA1/2 gene alteration.[45]

While the specific mechanisms that contribute to differences in responses to education about hereditary breast cancer and genetic testing among African-American women and Ashkenazi Jewish women are unclear, it is possible that education and counseling provide in-person increased motivations to have genetic testing among African-Americans because they had a high level of trust in the nurse educator who delivered the intervention.[40] The education and counseling sessions for the majority of the African-American participants were completed by an African American nurse educator.[46] Emphasis on interpersonal relationships is a key component of African-American culture, and it is possible that women were able to identify more strongly with the African-American nurse during the education session. This process may have contributed to increased genetic testing motivations.

Previous research has shown that ethnic identity or the level of affiliation with one's ethnic or racial group is associated with responses to breast cancer risk education and counseling. Improvements in risk comprehension and reductions in cancer-related distress were associated with higher levels of African-American ethnic identity among women who participated in a breast cancer risk education program that was delivered in a group format.[47] The process of identifying with women who are of the same ethnic background may be one mechanism through which African-American women comprehend cancer risk information. However, it is also likely that the specific beliefs and values related to interpersonal relationships, temporal orientation, and religion and spirituality that are highly endorsed within one's cultural worldview also have a direct influence on responses to risk information and counseling provided within genetic counseling and testing settings.[48]

Cultural Considerations in Genetic Counseling for BRCA1/2 Mutations

In most clinical research settings, predictive genetic testing for BRCA1/2 mutations is offered to individuals who have a minimum 10% to 20% prior probability of having a deleterious BRCA1/2 mutation.[49] It is standard practice to provide pretest education about hereditary breast cancer, the probability of having a BRCA1/2 gene alteration, and information about the benefits, limitations, and risk of genetic testing in order to facilitate informed decision-making about genetic testing.[49,50] Post-test counseling is also provided to improve adjustment to BRCA1/2 test results and enhance informed decisions about cancer prevention, surveillance, and treatment.[49,50]

While provision of risk information is one of the key aspects of genetic assessment and counseling, temporal orientation may influence the salience of risk information. Temporal orientation is described as the level of cognitive involvement within past, present, and future dimensions, and greater levels of future temporal orientation have been associated with improved psychological functioning following traumatic events.[51] It is possible that cancer risk estimates may be more meaningful among individuals with a future temporal orientation because they increase perceptions of control. However, among individuals with a present or past temporal orientation, estimates of genetic probability and disease risk may be less meaningful because there is little focus on the immediate situation.[48]

Previous research conducted among African Americans and Whites affected with hypertension has shown that individuals who had a present temporal orientation reported lower perceptions of the efficacy of disease prevention and control, as well as lower perceptions of susceptibility to the consequences of uncontrolled hypertension.[52] In this study, as well as in studies conducted among individuals from the general population, African Americans were significantly more likely than Whites to have a present temporal orientation.[52,53]

Previous studies have shown that greater levels of spiritual faith were associated with lower rates of test acceptance in a prior study by Schwartz and colleagues.[39] However, religious and spiritual beliefs may play a significant role in coping with genetic risk information among African-American women. Spirituality and religion are critical aspects of African-American culture,[46] and previous research has shown that African-American women affected with breast cancer were more likely than white women to use religious coping strategies and resources to adjust to their breast cancer diagnosis and treatment.[54] Religious coping strategies may also be used by African-American women to cope with genetic risk information. However, the psychological impact of genetic testing for BRCA1/2 mutations among African-American women and the effectiveness of religious coping strategies has not been evaluated among high-risk African-American women who have received BRCA1/2 test results.

Conclusion

Genetic counseling and testing for BRCA1/2 mutations is increasingly being integrated into the clinical management of individuals who have a family history of disease that is suggestive of inherited cancer susceptibility. A substantial amount of research has been conducted to understand the clinical, psychological, and familial impact of genetic testing for BRCA1/2 mutations. While few studies have addressed these outcomes among ethnically diverse populations, our knowledge about the prevalence of BRCA1/2 genes among these populations is increasing. For example, recent studies have shown that the prevalence of BRCA1/2 susceptibility genes is 12% to 21% among African-American hereditary breast cancer families. This finding provides support for the need for future studies designed to clarify the penetrance of BRCA1/2 mutations among this population. However, this review has demonstrated that reduced participation of African Americans in cancer genetics research is consistent. This is likely to be a significant limitation of future cancer genetics research, and increased culturally sensitive community outreach efforts may be needed to educate lay audiences about the availability of genetic counseling and testing or to recruit African Americans into cancer genetics research protocols.

This review has also demonstrated that ethnic background influences responses to information about hereditary breast cancer and genetic testing. However, the mechanisms that contribute to ethnic differences in responses to education about hereditary breast cancer are not clear. Additional research is needed to evaluate the influence of specific cultural beliefs and values on psychological and behavioral responses to genetic counseling and testing.●●●

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IN PRESS – PATIENT EDUCATION AND COUNSELING

Original Article

Sociocultural Influences on Participation in Genetic Risk Assessment and Testing among African American Women

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Sociocultural Influences on Participation in Genetic Risk Assessment and Testing among African American Women

Abstract

The objectives of this observational study were to describe the associations between cultural beliefs and values and participation in genetic risk assessment and testing among African American women at high risk for having a BRCA1 or BRCA2 (BRCA1/2) gene alteration. Subjects were 28 high-risk women who self-referred to a genetic counseling and testing research program. Overall, 61% subjects received BRCA1/2 test results and 39% declined. Mean levels of fatalistic beliefs about cancer and future temporal orientation were higher among test acceptors relative to decliners. Sociodemographic factors were not associated with test acceptance; however, rates of test acceptance were lower among women with greater perceptions of familial interdependence (41% versus 91%, $p = .02$). The results of this study suggest that cultural beliefs and values may influence genetic testing decisions among African American women.

Key Words: African American, Genetic Testing, Cultural Beliefs and Values

1. Background

Recently, epidemiological studies on hereditary breast cancer among African Americans have shown that the prevalence of deleterious BRCA1/2 mutations ranges between 12% to 21% [1-3]. Women who are found to carry a risk conferring BRCA1/2 gene alteration have an estimated 55%-85% increased risk of developing breast cancer and a 15%-60% increased risk of developing ovarian cancer [4-6]. In addition to providing personal cancer risk information, BRCA1/2 test results also have important implications for family members. First-degree relatives of BRCA1/2 mutation carriers have a 50% risk of testing positive for the BRCA1/2 gene alteration identified in a family member, while in most cases, offspring are not at risk for having an inherited alteration if a deleterious gene alteration is not identified in an affected family member.

Recent research has shown that interest in genetic testing may be high among African American women. For example, 82% of high-risk African Americans reported that they would definitely have genetic testing for BRCA1/2 mutations [7]. However, high levels of interest in genetic testing may not translate into similar rates of acceptance. Even though expectations about the positive outcomes of genetic testing were significantly greater among African American women than among Caucasian women [8], only 49% of African American women participated in an education session about hereditary breast cancer compared to 68% of Caucasian women [9]. Participation in genetic risk assessment and testing may be especially beneficial for African American women who have greater rates of early onset disease and suffer from higher rates of breast cancer mortality [10,11]. Even if women ultimately decide not to have testing, participation in risk assessment may be useful for African American women to increase knowledge about breast cancer risk factors and to provide information about options for

cancer prevention and control. However, barriers to utilization of genetic testing among African Americans may include the costs and availability of testing, concerns about exploitation, and distrust of the medical community [7, 12-15]. Cultural beliefs and values may also influence decisions about participating in genetic risk assessment and testing; however, little is known about cultural barriers and facilitators of participation specifically among African Americans.

Previous research has shown that cultural factors may influence decisions about breast cancer screening and treatment among African American and Caucasian women [16,17]; however, cultural factors have been inferred from ethnic differences in attitudes or from folk health beliefs in these studies. This method of evaluating cultural factors may not identify the specific components of culture that contribute to ethnic differences in cancer screening and treatment because ethnicity is only an approximation of deep cultural characteristics [18] and folk health beliefs may have limited generalizability. Understanding cancer prevention and control behaviors using cultural worldviews as a framework may provide more specific information on the influence of cultural beliefs and values on cancer screening and treatment behaviors among African American women.

Cultural worldviews are described as an intersecting system of philosophical beliefs and assumptions regarding the nature of reality, knowledge acquisition, behavioral perspective, and temporal orientation that are reflected in values, beliefs, and behaviors among members of an ethnic group [19,20]. Worldview values and beliefs within African American culture that may be relevant to participation in genetic counseling and testing include an increased emphasis on interpersonal relationships or communalism, and religion and spirituality [21]. Temporal orientation, or how one perceives the significance of events and the consequences of their actions in terms of past, present, and future implications may also influence cancer prevention and

control behaviors [22-24], however, limited information is available on temporal orientation, communalism, or religious coping styles among African American women at increased risk for developing cancer. A better understanding of how these cultural worldview beliefs and values influence cancer prevention and control behaviors among African American women is needed to develop culturally sensitive interventions. Therefore, we conducted a prospective observational study to describe the participation in genetic risk assessment and testing based on cultural beliefs and values among African American women at high-risk for having a BRCA1/2 gene alteration. Because cultural worldwide beliefs and values have not been evaluated specifically among this population, a second objective of this study was to describe these factors based on sociodemographic characteristics.

2. Methods

2.1. Participants

Eligible subjects were African American women ages 18 and older who had a minimum 10%-20% prior probability of having a BRCA1/2 mutation based on their family history of disease. Subjects were identified through mammography and oncology clinics and were invited to participate in a genetic counseling and testing research program offered at the Lombardi Cancer Center. This research was approved by the Institutional Review Board at the Georgetown University Medical Center.

2.2. *Procedures*

Women who self-referred to the risk evaluation and testing program and had a family history of breast cancer that was suggestive of hereditary breast cancer were contacted by a

professional telephone interviewer to complete a structured 40-minute baseline telephone interview. This interview included measures of sociodemographic characteristics and personal and family history of cancer. Cultural factors were also assessed at baseline; however, to minimize respondent burden, these instruments were mailed to subjects. Those who did not return completed questionnaires within two weeks were contacted by telephone to ensure that the questionnaires had been received and at this time, subjects were given the option of completing the cultural beliefs and values questionnaires over the telephone.

Subjects who agreed to participate in the genetic counseling program completed a pre-test education session. The pre-test education and counseling session was conducted individually by a genetic counselor or oncology nurse educator and lasted for about 1-hour. After obtaining written informed consent, participants were provided with information about hereditary breast cancer (i.e., comparison between genetic, familial, and inherited cancer, definition of susceptibility genes), the process of genetic testing (i.e., description of the testing sequence), and the benefits, limitations, and risks of testing (i.e., learning cancer risk information, possible difficulties in interpreting test results, potential impact of genetic test results on insurance). At the end of this session, participants were given the option of providing a blood sample for genetic testing. Full sequence testing of BRCA1/2 genes was performed by a commercial laboratory and costs for all genetic counseling and testing were paid by institutional funds. Subjects who provided a blood sample for testing were notified when test results became available and were invited to participate in a test results disclosure session.

The test result disclosure session was also conducted individually by a genetic counselor or an oncology nurse educator. Written informed consent was obtained prior to test results disclosure and along with BRCA1/2 test results, subjects received information about risk

management options [25] and were provided with a written report that included an interpretation of their BRCA1/2 test result and recommendations for cancer surveillance. Participants who received BRCA1/2 test results were contacted by a genetic counselor or oncology nurse educator approximately two weeks following the test result disclosure session to answer any additional questions and to provide referrals, if needed. Participants were also contacted for follow-up telephone evaluations of psychological functioning and cancer screening and prevention behaviors at 1-, 6-, and 12-months following test results disclosure. Because we were interested in participation in genetic risk assessment and testing, we focused only on data obtained at baseline and from study records.

2.3. Study variables

2.3.1. Sociodemographics

Likert-style items were used to obtain marital status (1 = single or never married, 2 = married or living as married, 3 = divorced or separated, and 4 = widowed), income level (1 = less than $20,000, 2 = $20,001-$35,000, 3 = $35,001-$50,000, 4 = $50,001-$75,000, 5 = greater than $75,000), education (1 = 8 or less years of school, 2 = some high school, 3 = high school graduate or GED, 4 = some college, and 5 = college graduate or more), and employment status (1 = not employed, 2 = employed full-time, 3 = employed part-time, 4 = retired) during the baseline telephone interview. We re-coded these items into dichotomous variables (i.e., married versus not married, employed versus not employed) based on the frequency of responses. Age was determined based on the subject's date of birth; subjects were categorized as being less than

or equal to age 50 or older than age 50 because this was the criteria used to determine if one's family history of cancer was suggestive of hereditary breast cancer.

2.3.2. Cancer Status

Personal and family history of breast and/or ovarian cancer was evaluated during the baseline telephone interview.

2.3.3. Cultural beliefs and values

Cultural beliefs and values were assessed in terms of three dimensions: (1) communalism, (2) temporal orientation, and (3) religious coping style. Because previous research has shown that fatalistic beliefs about cancer are associated with utilization of cancer screening tests among African Americans [26], we also evaluated this variable in our study.

2.3.3.1. Communalism. We used the Communalism Scale [27] to measure perceptions of the importance of family and social relationships. The Communalism Scale is a 31-item Likert-style instrument that assesses perceptions of the importance of familial and social interdependence (1=Completely False, 2=Mostly False, 3=Neutral, 4=Mostly True, and 5=Completely True). The Communalism Scale had good internal consistency in this sample (Cronbach's alpha=.77).

2.3.3.2. Temporal orientation. We used the Temporal Orientation Scale (TOS) to evaluate time orientation. The TOS is a 26-item Likert-style scale and previous research has shown that the scale consists of three highly reliable factors for past (i.e., I think about the past a lot), present (i.e., I believe what is done is done so it is better to move on than dwell in the past), and future (i.e., I try to do things that will help me get what I want in the future) temporal

orientation [28]. We used these three factors to measure temporal orientation in this study; the internal consistency coefficients for past, present, and future dimensions ranged from .81 to .85 in this sample.

2.3.3.3. Religious coping style. The short-form of the Religious Coping Style Scale (RCSS) [29] was used to measure religious coping styles. The RCSS is an 18-item Likert style scale that measures utilization of coping strategies (1 = Never, 2 = A little of the time, 3 = Some of the time, 4 = Most of the time, 5 = Always). Previous research has shown that the RCSS consists of three highly reliable religious coping factors (collaborative, self-directing, and deferring) that are associated significantly with levels of religious involvement and competence [29]. These scales had good internal consistency in this sample and the Cronbach's alpha coefficients for the coping styles ranged from .78 to .88.

2.3.3.4. Cancer fatalism. We used the Cancer Fatalism Inventory (CFI) [26] to measure fatalistic beliefs about cancer. The CFI is a 15-item instrument that evaluates perceptions of the certainty of death, pessimism, and fear surrounding cancer diagnosis and treatment. Although previous studies have used a true-false response format for items [26], we used a five-point Likert-scale (1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, and 5=Strongly Agree) to assess fatalistic beliefs about cancer in this study because we were interested in the level of endorsement for each fatalism item. Consistent with previous reports [26], higher scores indicated greater levels of fatalistic beliefs.

2.4. Participation in genetic risk assessment and testing

Participation in genetic risk assessment and testing was determined from study records. Subjects who completed the genetic risk assessment and test results disclosure sessions were

categorized as acceptors. Decliners included subjects who elected to not participate in genetic risk assessment and counseling and those who participated in genetic risk assessment, but elected to not receive test results. Even though subjects could elect to decline participation at any point in this study, including after provision of a blood sample for testing, there were no subjects in this study who declined to receive BRCA1/2 test results after providing a blood sample for testing; thus, all subjects who were categorized as acceptors completed the pre-test education and test results disclosure sessions described above.

2.5. Data analysis

We generated frequencies to characterize the study sample in terms of sociodemographic factors, cancer status, and participation in genetic risk assessment and testing. Because the sample consisted of only 28 women, our analyses were primarily descriptive. Specifically, we generated means with 95% confidence intervals to characterize levels of each cultural factor based on participation status (accept versus decline). We used this same procedure to describe levels of cultural beliefs and values based on sociodemographic characteristics. For these analyses, we used the binary variables described above under section 2.3.1. Because of the small sample size, we used Fisher's Exact Tests to describe the association between sociodemographic characteristics and participation status.

Because our prior work has shown that concerns about the familial and emotional impact of testing may be important reasons why African American women may not want to have genetic testing [8], we evaluated participation rates based on responses to items in the communalism and collaborative religious coping style scales. For these analyses, we re-coded communalism and collaborative religious coping items into binary variables (mostly/completely true *versus*

mostly/completely false/neutral for communalism items and never/a little of the time/some of the time *versus* most of the time/always for collaborative religious coping items) and used Fisher's Exact Tests to evaluate the association between these binary items and participation status.

3. Results

3.1. Sample characteristics

Subjects in this study were recruited as part of an initiative to increase access to genetic counseling and education among African American women and a total of 45 eligible women were identified during the 1-year study period. Of these, 28 completed the baseline telephone interview. Because sociodemographic factors were obtained during the baseline telephone interview, it was not possible to compare respondents who completed the baseline to those who did not to complete the baseline in terms of sociodemographic factors or other characteristics.

The final sample consisted of 28 African American women at high risk for having a BRCA1/2 gene alteration. With the exception of one subject, all women were the first family member to undergo genetic testing and were affected with either breast and/or ovarian cancer. In terms of sociodemographics, most subjects were age 50 or less (68%), were not married (64%), had some college education (61%), and were employed (71%). In addition, 63% of subjects had a household income of $50,000 or less.

3.2. Association between sociodemographic characteristics and cultural factors

As shown in Table 1, temporal orientation differed only based on education level. Specifically, mean levels of past temporal orientation were higher among subjects with lower

education levels (M = 49.9, 95% confidence interval = 45.8, 53.9) relative to subjects with higher education levels (M = 39.1, 95% confidence interval = 33.2, 44.9). Mean levels of fatalistic beliefs about cancer, religious coping style, communalism, and future temporal orientation did not differ among subjects based on their age, marital status, employment status, or income level.

3.3. Participation in genetic risk assessment and testing

Among the participants in this study (n=28), 61% (n=17) participated in genetic risk assessment and received BRCA1/2 test results and 39% (n=11) declined. As shown in Table 2, rates of participation in genetic risk assessment and testing did not differ based on age, marital status, income, education, or employment status. Because of the small sample, some of these differences are quite substantial. However, test acceptors had higher levels of fatalistic beliefs about cancer relative to decliners (see Table 3). Mean levels of future temporal orientation also higher among test acceptors (M = 44.5) relative to test decliners (M = 37.7); however, as shown in Table 3, there was some slight overlap in the confidence intervals for the mean values. Mean levels of religious coping styles, communalism, and past and present temporal orientation were not different among test acceptors and decliners.

In term of participation by responses to communalism and religious coping items, only the communalism belief regarding familial interdependence was associated with genetic test acceptance and women who responded that it was most or completely true that individuals should not view themselves as being independent from family members were less likely to participate in genetic risk assessment and testing. Forty-one percent of respondents who endorsed this belief received their BRCA1/2 test results compared to 91% of respondents who did not endorse this belief (p = .02). There was also a trend for respondents who reported greater

utilization of coping by working together with God when considering a difficult situation to be more likely to participate in genetic risk assessment and counseling (70%) compared to respondents who reported less utilization of this strategy (20%) ($p = .06$).

4. Discussion

Previous research has shown that African American women may have a high level of interest in genetic testing for BRCA1/2 mutations [7]; however, this is the first study to describe rates of participation in genetic risk assessment and testing among African American women at high risk for having a BRCA1/2 gene alteration based on their cultural beliefs and values. In this study, 61% of the subjects in this study received BRCA1/2 test results and participation rates did not differ based on sociodemographic characteristics. However, mean levels of fatalistic beliefs about cancer and future temporal orientation were higher among test acceptors relative to decliners.

Previous research has suggested that ethnic differences in temporal orientation may contribute to differences in perceived risk of developing breast cancer among African American and Caucasian women [30] and the results of this study provide empirical evidence that temporal orientation may influence participation in cancer risk counseling among African American women. Temporal orientation is described as how one perceives the significance of events and the consequences of one's behavior in terms of past, present, and future implications. Greater levels of future temporal orientation have been associated with improved psychological functioning following traumatic events and health beliefs [22,24]. For example, in a study conducted among African Americans and Caucasians affected with hypertension, individuals who had higher levels of future temporal orientation were more likely to report greater perceived

susceptibility to the consequences of uncontrolled hypertension and greater perceptions of the benefits of medical treatment [22]. It is likely that mean levels of future temporal orientation are higher among test acceptors relative to decliners because this temporal dimension contributes to greater perceptions of the value of genetic risk information. It is also possible that future temporal orientation is associated with a greater perceived risk of having a BRCA1/2 gene alteration and also shapes beliefs regarding the value of BRCA1/2 test results to provide younger generations of their family with information that would help to reduce or eliminate the family's cancer burden. Although higher levels of future temporal orientation were observed among test acceptors in this study, previous research has shown that flexible temporal orientation with an emphasis on both past and present dimensions may be more common among African Americans [31] and when compared to Caucasians, African Americans reported greater levels of present temporal orientation related to health outcomes [22]. Because this study only included African American women, we were not able to compare ethnic differences in past, present, or future temporal orientation and we also did not attempt to determine whether past, present, or future temporal dimensions were the most salient to women because of the small sample size. Future studies with larger and more ethnically diverse samples should assess these effects as well as evaluate the association between temporal orientation and perceived risk of having a BRCA1/2 gene alteration.

We also found that test acceptors reported higher levels of fatalistic beliefs about cancer. This finding differs from previous studies in which higher levels of cancer fatalism was a barrier to utilization of cancer screening tests and lower interest in genetic testing for inherited prostate cancer risk [26,32]. However, these previous studies were conducted among individuals who did not have a personal history of cancer. The results of our study suggest that fatalistic beliefs

about cancer may have a different impact on health-related behaviors among women who have a personal history of disease. Previous research has shown that African American women have lower levels of knowledge about breast cancer genetics [7,8] and it may be that women interpreted their personal history of cancer as an indication that they also carried a risk-conferring BRCA1/2 gene alteration. Although greater sensitivity to cultural worldview beliefs and values in health education programs is needed [18], this finding underscores the importance of continuing to provide education about hereditary breast cancer and BRCA1/2 mutations as part of culturally sensitive counseling programs.

Specific components of communalism and religious coping were also associated with participation in genetic risk assessment and testing in this study. Participation rates were lower among women who reported that individuals should not view themselves as independent from family members compared to women who did not endorse this belief. This finding may explain why African Americans report fewer concerns about individual autonomy [33] and are more concerned about the familial impact of genetic testing for inherited breast cancer risk [8]. Although women with higher levels of spiritual faith were significantly less likely to receive BRCA1/2 test results in a prior study [34], there was a trend for women who reported greater use of working together with God when considering difficult situations to be more likely to participate in genetic risk assessment and testing in this study. While prior reports have suggested that religious beliefs about disease causation may be a barrier to participation in genetic testing and may delay seeking treatment for breast cancer symptoms [16,17], recent work has shown that African American women affected with breast cancer use religious coping strategies to adjust to their diagnosis [35]. Working with God may be one strategy that African American women use to make decisions about whether or not to participate in genetic risk

assessment and testing. It may be that the impact of religious beliefs about disease causation (i.e., cancer is a punishment from God) differs from that of collaborative religious coping strategies that increase perceptions of control in a difficult situation [36]; however, additional research is needed to evaluate the effects of religious beliefs about disease causation relative to the effects of religious coping style.

This is the first study to describe participation in genetic risk assessment and testing based on cultural beliefs and values among high-risk African Americans; however, there are several limitations that should be noted. First, this was an observational study conducted among a small sample of African American women. This restricted our statistical analyses to univariate comparisons, which may limit the generalizability of our findings; however, the challenges associated with recruiting African Americans to participate in cancer prevention and control trials are well documented. While additional research is needed on genetic test acceptance among larger samples of high-risk African Americans, this is the first study to report rates of genetic test acceptance based on cultural beliefs and values. These findings extend our understanding of participation barriers and facilitators among African American women beyond evaluations of the effects of attitudes about the benefits, limitations, and risks of genetic testing on testing decisions. An additional consideration is that the rates of genetic test acceptance observed among this sample may not be comparable to settings in which genetic counseling and testing are not provided free of charge. Despite these limitations, the results of this study have important implications for how cancer risk education and counseling are provided to African American women.

5. Practice implications and conclusions

Genetic risk assessment and testing are now being integrated into the clinical management of individuals who have a family history of breast and/or ovarian cancer that is suggestive of inherited cancer risk. Our data suggest that beliefs and values surrounding communalism and religious coping could be used as the basis for providing culturally sensitive genetic counseling to African American women. Culturally sensitive educational materials have been shown to increase comprehension of complex medical topics among members of minority groups [37] and cultural beliefs and values evaluated in this study may also need to be integrated into cancer risk assessment programs targeted to African Americans, regardless of their sociodemographic background. In this study, beliefs and values surrounding familial relationships and interdependence and collaborative religious coping did not vary among women based on sociodemographic factors. Community outreach efforts designed to educate lay audiences about the availability of genetic risk assessment or to recruit African Americans into cancer genetics research protocols may also need to include a more elaborate discussion about the possible positive impact of testing on family relationships. Outreach efforts in the African American community should also seek to reinforce and validate the belief that cancer can be combated through a collaborative relationship with God that involves a combination of spiritual faith and personal proactive health behaviors, including genetic testing for individuals with a personal and family history of cancer. Further, it is likely that cultural beliefs and values that influence decisions about participation in genetic risk assessment and testing may also influence psychological and behavioral reactions to BRCA1/2 test results. Thus, post-test counseling and education may need to address fatalistic beliefs about BRCA1/2 test results through emphasis on the implications of genetic risk information for cancer screening and risk behaviors.

The results of this study provide preliminary information on decisions about participating in genetic risk assessment and testing based on cultural beliefs and values among high-risk African American women. Test acceptors had higher levels of future temporal orientation and fatalistic beliefs about cancer. Additional research is needed on the influence of cultural beliefs and values on the psychosocial and behavioral outcomes of genetic testing among African American women and intervention studies are needed to evaluate the impact of culturally sensitive genetic counseling and education programs among this population.

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Table 1. Sociodemographic Factors by Cultural Beliefs and Values

Variable	Level	Cultural Factor *Mean* (S.D.) and [95% Confidence Interval]							
		CFI	**COM**	**DRC**	**CRC**	**SRC**	**PTP**	**FTP**	**PSP**
Age	LE 50	*31.2* (9.4) [26.7, 35.8]	*112.3* (11.4) [106.8, 117.8]	*19.6* (6.9) [16.3, 22.9]	*23.7* (6.2) [20.7, 26.7]	*10.8* (4.9) [8.4, 13.1]	*33* (7.6) [29.4, 36.7]	*42.9* (9.5) [38.4, 47.6]	45.8 (10.2) [40.8, 50.7]
	GT 50	*31.3* (7.6) [25.5, 37.1]	*116.7* (13.4) [105.8, 126.4]	*18.6* (7.5) [12.8, 24.3]	*26.2* (3.2) [23.7, 28.6]	*11.3* (6.4) [6.4, 16.3]	*28* (6.7) [22.8, 33.2]	*39.3* (6.8) [34.1, 44.5]	45.3 (9.0) [38.4, 52.2]
Marital Status	Married	*29.5* (8.1) [23.7, 35.9]	*113.6* (13.2) [104.1, 123]	*19.2* (6.8) [14.3, 24.1]	*24.2* (3.4) [21.8, 26.6]	*12.3* (5.3) [8.5, 16.1]	*34* (6.7) [29.3, 38.8]	*43.8* (8.1) [38, 49.6]	*45.3* (8.3) [39.3, 51.2]
	Not Married	*32.3* (9.1) [27.8, 36.8]	*113.5* (11.6) [107.7, 119.2]	*19.3* (7.2) [15.7, 22.9]	*24.6* (6.4) [21.4, 27.8]	*10.2* (5.3) [7.6, 12.8]	*29.9* (7.8) [26, 33.8]	*40.7* (9.2) [36.2, 45.3]	*45.8* (10.6) [40.6, 51.1]
Education Level	Some College	*30.5* (10) [25.3, 35.6]	*115.6* (10.3) [110.3, 120.9]	*20.1* (6.3) [16.8, 23.3]	*24.7* (4.5) [22.4, 27.1]	*11.1* (4.6) [8.7, 13.4]	*33* (8.4) [28.7, 37.3]	*43.8* (7.2) [40.1, 47.5]	*49.9* (7.9) [45.8, 53.9]
	College Graduate	*32.5* (6.4) [28.2, 36.8]	*110.2* (14.0) [100.8, 119.7]	*18.0* (8.0) [12.6, 23.4]	*24.1* (6.9) [19.4, 28.7]	*10.8* (6.5) [6.5, 15.2]	*29* (5.6) [25.2, 32.7]	*38.7* (10.3) [31.8, 45.6]	*39.1* (8.7) [33.2, 44.9]
Employment Status	Employed	*30.8* (8.5) [26.8, 34.8]	*112.1* (10.5) [107.1, 117]	*20.1* (6.3) [17.2, 23]	*24.2* (6.1) [21.3, 27]	10.6 (4.8) [8.4, 12.9]	*31.8* (6.6) [28.7, 34.9]	*41.9* (9.0) [37.7, 46.1]	*44.9* (9.0) [40.7, 49.1]
	Not Employed	*32.5* (9.7) [24.4, 40.6]	*117.1* (15.1) [104.4, 129.7]	17.1 (8.4) [10, 24.2]	*25.3* (3.4) [22.5, 28.2]	*11.8* (6.7) [6.2, 17.3]	*30.4* (10.1) [22, 38.8]	*41.6* (8.7) [34.4, 48.9]	*47.5* (11.7) [37.8, 57.2]
Income Level	LE $50,000	*32.2* (9.5) [27.3, 37]	*112.4* (13.7) [105.3, 119.4]	*19.8* (6.2) [16.6, 22.9]	*25.1* (4.7) [22.7, 27.5]	*11.8* (5.7) [8.9, 14.7]	*31.5* (7.6) [27.5, 35.4]	*42.4* (5.8) [39.4, 45.4]	*48.5* (8.9) [43.9, 53]
	GT $50,000	*30.6* (7.5) [25.2, 36]	*113.7* (7.8) [108.1, 119.2]	*19.4* (8.1) [13.6, 25.2]	*23.6* (6.9) [18.6, 28.6]	*9.5* (4.8) [6.0, 13]	*30.6* (7.9) [25, 36.3]	*39.9* (12.5) [31, 48.8]	*40.6* (9.8) [33.6, 47.6]

***Mean (S.D.) {Range} for Cultural Beliefs and Values in Total Sample**

COM = Communalism: Mean = 113.5 (12) {49}
CFI = Cancer Fatalism: Mean = 31.3 (8.7) {32}
SRC = Self-Directed Coping: Mean = 11 (5.3) {20}
CRC = Collaborative Religious Coping: Mean = 24.5 (5.5) {24}
DRC = Deferring Religious Coping: Mean = 19.2 (6.9) {24}
PTP = Present Temporal Orientation: Mean = 31.4 (5.3) {33}
FTP = Future Temporal Orientation: Mean = 41.8 (8.8) {40}
PSP = Past Temporal Orientation: Mean = 45.6 (9.7) {47}

Table 2. Participation in Genetic Risk Assessment and Testing by Sociodemographic Characteristics

Variable	Level	% Accept	P-Value*
Education Level	Some College	53%	.45
	College Graduate	70%	
Marital Status	Not Married	40%	.12
	Married	72%	
Income Level	GT $50,000	60%	.31
	LE $50,000	65%	
Employment Status	Employed	65%	.67
	Not Employed	50%	

Table 3. Mean Levels of Cultural Beliefs and Values by Participation Status

Variable	Participation Status	
	Accept Mean (S.D.) [95% Confidence Interval]	**Decline Mean (S.D.) [95% Confidence Interval]**
Fatalism	34.8 (8.1) [30.6, 39]	25.8 (6.7) [21.3, 30.3]
Communalism	113.5 (11.4) [107.7, 119.4]	113.5 (13.4) [104.5, 122.4]
Collaborative Religious Coping	25.3 (5.8) [22.3, 28.3]	23.2 (4.9) [19.9, 26.5]
Deferring Religious Coping	19.1 (8.1) [14.9, 23.2]	19.5 (5.0) [16.2, 22.9]
Self-Directed Coping	11.1 (5.5) [8.3, 14]	10.7 (5.2) [7.3, 14.2]
Future Temporal Orientation	44.5 (6.4) [41.2, 47.8]	37.7 (10.6) [30.6, 44.8]
Present Temporal Orientation	32.4 (5.6) [29.6, 35.3]	29.8 (10.0) [23.1, 36.5]
Past Temporal Orientation	45.9 (10.2) [40.7, 51.2]	45.2 (9.2) [39, 51.4]